DOCUMENT RESUME

ED 398 710 EC 305 003

AUTHOR Hulgin, Kathy; And Others
TITLE Innovative Practices in Supported Living: An Overview of Organizations, Issues, and Resource Materials.
INSTITUTION Syracuse Univ., NY. Center on Human Policy.
SPONS AGENCY National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
PUB DATE May 96
CONTRACT H133D50037
NOTE 69p.
PUB TYPE Information Analyses (070) -- Reference Materials - Bibliographies (131)

EDRS PRICE MF01/PC03 Plus Postage.
DESCRIPTORS Delivery Systems; *Disabilities; *Housing; *Independent Living; Individualized Programs; Information Sources; Innovation; Personal Autonomy; Program Development; Social Change
IDENTIFIERS *Supported Housing

ABSTRACT

This packet of information focuses on innovative practices related to supported living for people with disabilities. It opens with an article by John O'Brien, "Supported Living: What It's Not," which summarizes common misunderstandings of supported living. The next section describes eight innovative agencies in the area of support living. The common attributes of these successful agencies are identified and include small size, nonhierarchical, nonbureaucratic, and have a personal structure; leadership driven by people and values; clear work principles; an image defined by issues which affect people's lives rather than narrow service categories; and an openness to change. Two additional agencies that are in the process of developing supported living services are also described. A section on considerations in implementing supported living discusses housing, support, person-centered planning, individualized funding, and service brokerage. The final section lists resources for additional information, including organizations, available written materials, and World Wide Web sites on the Internet. (CR)

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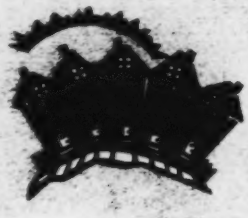

INNOVATIVE PRACTICES IN SUPPORTED LIVING: AN OVERVIEW OF ORGANIZATIONS, ISSUES, AND RESOURCE MATERIALS

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May 1996

The preparation of this information package was supported in part by the National Resource Center on Community Integration, Center on Human Policy, School of Education, Syracuse University, through the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133D50037. No endorsement by the U.S. Department of Education should be inferred. The authors would like to thank Steve Taylor, John O'Brien, Jay Klein, and Rachael Zubal for their contributions in the development of this resource package.

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INTRODUCTION

Supported living has developed over the past ten years or so as the practice of supporting people, even those with severe disabilities, to live in their own homes, gain control in their lives, and to become valued members of their communities. Though supported living is associated with these general goals, specific outcomes for individuals and the process through which they are achieved cannot be prescribed. Service providers are learning through direct experience and from the experience of others to implement a supported living approach.

The Center on Human Policy has conducted research on the development of integrated services since 1985. Staff members have visited and learned from agencies around the country that have been the most successful in supporting people with severe disabilities to live in the community. This packet includes information about innovative practices related to supported living. It should be noted that there are issues related to community integration such as poverty, race, and gender that should be considered in developing supported living services. While some agencies are organizing in ways that address these concerns, the information presented here is not that broad in scope. It is designed primarily for service providers but should be helpful to individuals receiving services, their families, and advocates.

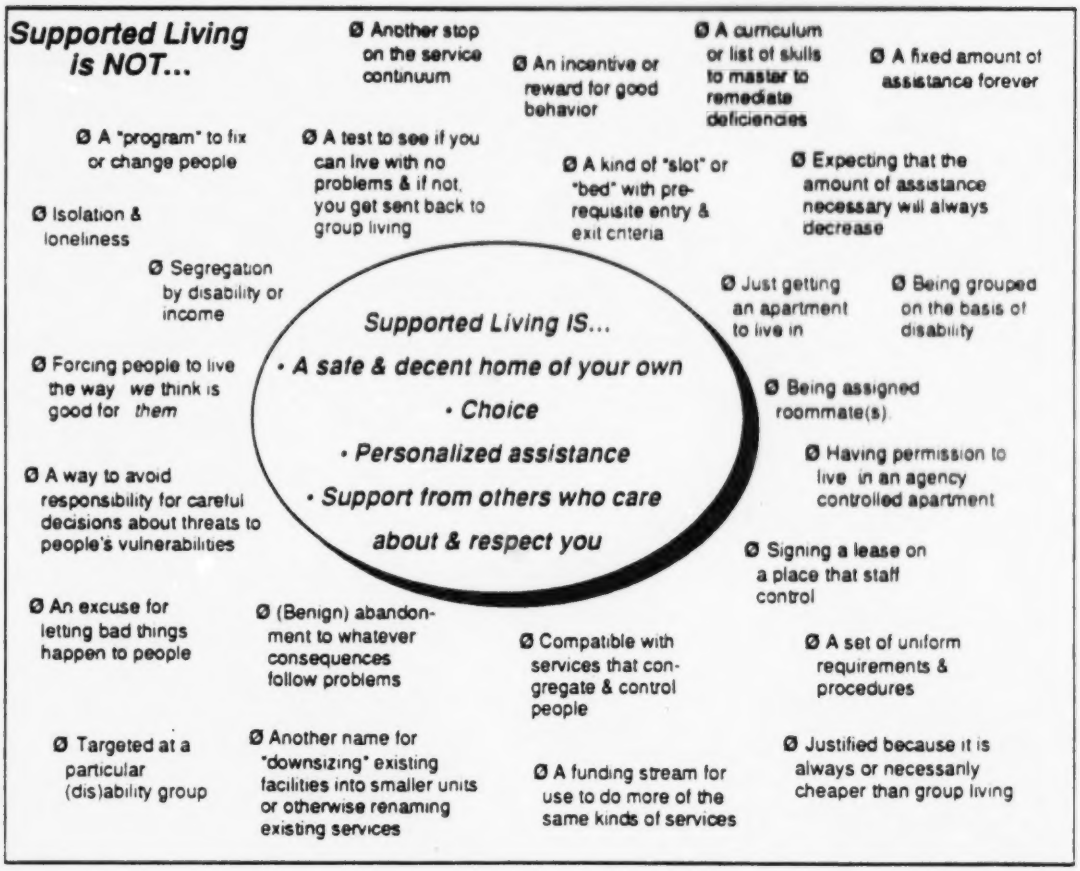
The packet begins with a definition of supported living developed by John O'Brien. This is followed by a section that lists and describes the efforts of innovative agencies around the country. The next section addresses a

number of issues that have recently emerged in the field as well as those which are important to continue to address in the effort to develop supported living services. Last, the packet contains an annotated bibliography and a list of relevant sources on the internet.

SUPPORTED LIVING: WHAT IT'S NOT

by John O'Brien

One way of defining supported living is to define its edges, by saying as clearly as possible what it is not. This diagram summarizes a number of misunderstandings of supported living encountered by many leaders in providing supported living.


Supported Living is NOT...
Ø Another stop on the service continuum
Ø An incentive or reward for good behavior
Ø A curriculum or list of skills to master to remediate deficiencies
Ø A fixed amount of assistance forever
Ø A "program" to fix or change people
Ø A test to see if you can live with no problems & if not, you get sent back to group living
Ø A kind of "slot" or "bed" with pre-requisite entry & exit criteria
Ø Expecting that the amount of assistance necessary will always decrease
Ø Isolation & loneliness
Ø Segregation by disability or income
Ø Just getting an apartment to live in
Ø Being grouped on the basis of disability
Supported Living IS...
• A safe & decent home of your own
• Choice
• Personalized assistance
• Support from others who care about & respect you
Ø Forcing people to live the way we think is good for them
Ø Being assigned roommate(s)
Ø Having permission to live in an agency controlled apartment
Ø A way to avoid responsibility for careful decisions about threats to people's vulnerabilities
Ø Signing a lease on a place that staff control
Ø An excuse for letting bad things happen to people
Ø (Benign) abandonment to whatever consequences follow problems
Ø Compatible with services that congregate & control people
Ø A set of uniform requirements & procedures
Ø Targeted at a particular (dis)ability group
Ø Another name for "downsizing" existing facilities into smaller units or otherwise renaming existing services
Ø A funding stream for use to do more of the same kinds of services
Ø Justified because it is always or necessarily cheaper than group living

INNOVATIVE AGENCIES

Supported living, as any service approach, must be considered in the context in which it is implemented. The approach has been most successfully implemented in agencies that have been developed for the sole purpose of providing supported living services. In most agencies, however, supported living requires adopting a different way of thinking and organizing resources. An increasing number of agencies that have a history of providing congregate services are successfully developing this approach through a conversion process.

This section describes examples of some of the agencies around the country that have been the most successful in implementing this approach.

Supported Living Agencies

A number of agencies around the country are committed to providing only supported living services. These agencies share several attributes that contribute to the successful implementation of this approach including:

1) They are small, nonhierarchical, nonbureaucratic, and personal.
2) Leaders are driven by people and values, rather than regulations and funding.
3) They have clear principles that drive their work.
4) They are not defined in terms of narrow service categories but by the issues which affect people's lives such as poverty.
5) They learn from experience and are open to change.

Described below are agencies that have taken the lead in successfully implementing supported living.

Options in Community Living
22 North Second Street
Madison, WI 53704
(608) 249-1585
Contact: Gail Jacob

Options in Community Living is a private, non-profit agency that provides support to approximately 100 people, including some with severe and multiple disabilities, to live in their own houses and apartments. The agency was one of the first in the United States to develop this approach. It originally developed a "clustered apartment" approach whereby people lived in neighboring apartments located in one complex. Now people live where they choose and with whom they choose--sometimes by themselves, sometimes with roommates.

About 24 people served by Options have paid roommates or personal care attendants to provide full-time support, using a variety of Medicaid and state funding mechanisms. For these people, Options acts as a broker--assisting them to recruit, screen, hire, supervise, and, if necessary, fire their attendants. Options also provides support to about 75 people who do not require live-in assistance but who may need intensive services and supports to remain in their homes.

The agency has three teams of "community support specialists" who provide support, case management, training, and other services. All team members know each person supported by their team and can give each other support and assistance as well as problem-solving help when a dilemma arises. One of the agency's priorities, in terms of support, is to assist people

to become part of their neighborhoods and communities, and significant staff time is devoted to this area.

This agency did not have the benefit of learning from the experience of others as it developed this approach and has relied on practices such as story telling and journal writing to reflect upon and learn from their own work. Some of the reflections of members have been compiled in Remembering the Soul of Our Work which is listed in the resource material section of this information package.

Neighborhood Connections
312 West Lakeside Street
Madison, WI 53715
(608) 251-1221
Contact: Sid Nichols
Maureen Quinlan

Neighborhood Connections is a non-profit agency that assists 19 people, most of whom have developmental disabilities and challenging behavior, to live in their own homes. The agency was formed by staff from Options in Community Living and is committed to supporting people for whom community living is often thought not possible.

Most people the agency supports need a great deal of assistance. Though situations vary, many people have live-in assistants and receive additional support. This agency is grounded in the belief that staying small and maintaining strong personal relationships with the people it supports provides a foundation for success.

Supported Community Living, Inc.
220 West Main Street
Midland, MI 48640
(517) 631-4439
FAX (517) 832-5528
Contact: Rebecca Shuman
Myrna Barlett

Supported Community Living, Inc. is a coalition of The Arc of Midland, Michigan, the David Reece Fund, and Services for People with Developmental Disabilities Midland-Gladwin Mental Health. The coalition is working in cooperation with the Department of Social Services to provide low cost housing and supported living opportunities for people with developmental disabilities. These services are directed by individuals and their families.

Supported Community Living, Inc. is interested in sharing what is has learned in this effort, particularly related to collaboration between agencies, individuals, and their families. Members are currently in the process of developing training materials and technical assistance services. The agency is open to arranging visits with individuals living in their own homes to learn how these situations were made possible. There is a fee for these visits. For more information, contact the persons listed above.

NABORS, Inc.
(Neighbours Allied for Better Opportunities
in Residential Support)
2 Carlton Street, Suite 1001
Toronto, ON M5B 1J3
CANADA
(416) 351-0095
Contact: Beth French

NABORS is a non-profit organization that was started in Toronto in 1984 by a group of individuals with disabilities, parents, and allies. They were interested in expanding the housing options for people with disabilities. Out of this evolved the creation of two housing cooperatives--Chord and Courtyard--based on a vision of inclusion and diversity across people of varying ages, income levels, abilities, and cultural origins. NABORS works in conjunction with the coops to support the active membership and participation of a small number of people with disabilities.

Specialized Community Care
P.O. Box 174
Bristol, VT 05443
(802) 453-4175
Contact: Scott Hill

Specialized Community Care was developed by former staff of Vermont's only institution. The agency's leadership is grounded in the commitment to supporting people with challenging behavior in the community. The agency supports 13 people, many of whom lived in the institution and were considered the most difficult to serve.

Each of these individuals shares a home with a person or a family who provides them with support. In addition, each person has a team of respite workers that is organized to provide regular assistance as well as support during difficult times. Overall, people who had much difficulty in the institution are living successfully in their own homes.

Job Path
22 West 38th Street
11th Floor
New York, NY 10018
(212) 944-0564
Contact: Fredda Rosen

Though Job Path has primarily provided support to people in community employment, it has recently shifted its focus to also supporting a small number of people in their living and social lives. This shift came about when agency leaders made a commitment to developing services that were responsive to the needs of people with severe disabilities.

Job Path's approach is based on the recognition that many people with severe disabilities have not had the opportunity to develop interests. Agency members work closely with individuals and their families to provide opportunities to explore their interests and make connections in their neighborhoods. See Job Path: Shifting the Focus Beyond Work in the annotated bibliography section.

Atlanta Alliance on Developmental Disabilities
Suite 105
215 Lakewood Way, S.W.
Atlanta, GA 30315
(404) 622-5343
Director: Mary Yoder

The Atlanta Alliance on Developmental Disabilities (formerly Project RESCUE) supports children and adults with disabilities and their families, many of whom experience poverty, homelessness, exploitation, abuse, and

discrimination. Forty-three percent of those served are mothers with a label of mental retardation. The Atlanta Alliance on Developmental Disabilities provides a wide range of supports to people, including: in-home assistance; help in obtaining housing, clothing, food, and furniture; transportation; support in work and recreation settings; assistance in making connections with neighbors and other community members and organizations; counseling; and support groups.

The guiding principles of the agency are that support approaches need to be personalized and that people need to be served on their turf. The relationship between the support staff and the family is critical. A chapter describing the efforts of this agency can be found in Life in the Community: Case Studies of Organizations Supporting People with Disabilities which is listed in the annotated bibliography section.

Training Toward Self-Reliance (TTSR)
2755 Cottage Way, #2
Sacramento, CA 95825
(916) 483-3817
Director: Charles Galloway

TTSR supports adults with developmental disabilities who live in their own homes and apartments. The agency places a priority on supporting people in ways that are not controlling. TTSR staff support a number of individuals with disabilities who are parents, and they support a number of people to manage their own personal care services. The agency uses person-centered planning as a vehicle to assist people to develop connections and relationships with other community members and organizations. Staff have

established key connections with a variety of generic service providers in the community. Overall, the agency has decided to limit its expansion in terms of numbers of people supported and instead focus on enhancing the quality of people's lives.

Agencies that are Converting to Supported Living Services

An increasing number of agencies that have a history of providing residential services in congregate settings are developing supported living services. It is very challenging to develop this approach in many agencies. Certain circumstances or opportunities contribute to an agency's success:

1) There must be opportunities for staff to try new things.
2) Staff who are involved in developing this approach must have a clear understanding of the distinction between supported living and other services the agency provides.
3) There must be the direct involvement of at least one person in authority who can bend or reinterpret rules to work through obstacles and pull in resources.

Given these circumstances, many agencies are successful in developing the approach at least for some people. The effort is vulnerable over time, however, if it is not given priority and viewed at an agency level as a direction for change. The following two agencies have made a commitment to convert to supported living services.

Jay Nolan Community Services
25006 Avenue Kearny
Valencia, CA 91355
(818) 700-7897
Contact: Jeff Strully

In less than a three year period, from 1992 to 1995, Jay Nolan Community Services converted its group homes to support all of the 64 people it serves in homes of their own. This was particularly challenging in that the agency serves people with autism who need a great deal of assistance. Change came about when the agency reached a crisis point, realizing that its current practices were not meeting the needs of these people.

After recruiting new leadership, the agency created the opportunity for people to live in their own homes as a first step or foundation to developing more supportive services. Now it is focusing on shifting decision making power from the agency to individuals and the people who know them well. In this effort, the agency is facilitating circles of support.

For a report describing this agency's conversion process, see Jay Nolan Community Services: The Challenges and Dilemmas of Quick Conversion from Group Homes to Supported Living listed in the annotated bibliography section.

Onondaga Community Living
Eastwood Office Complex
2827 James Street, Suite 215A
Syracuse, NY 13206
(315) 434-9597
Contact: Pat Fratangelo

Onondaga Community Living is a private non-profit agency that provides services to approximately 33 people. Though it has operated group homes since its formation in 1987, this agency has begun to develop supported living services. It has recently made the commitment to shift its services in this direction and, at the time of this report, had begun to close one of its three group homes.

This process of agency-wide change is occurring through a number of opportunities for members to reflect upon their work including discussions with outside consultants and an external evaluation.

CONSIDERATIONS IN IMPLEMENTING SUPPORTED LIVING

Supported living represents a new way of thinking about people with disabilities and the provision of services. In the movement to develop services that are more responsive, new ideas have emerged that are worthy of consideration. As described below, housing alternatives, support, person-centered planning, individualized funding strategies and service brokerage potentially offer new opportunities for people. These are, however, new ideas and the practical implications for people are only beginning to be understood.

Housing

Supported living is grounded in the principle that all people with developmental disabilities have the right to lease or own their own homes. Within the past few years, there have been many developments in the area of home ownership. Successful efforts have been possible through collaboration among individuals, their families, advocates, service providers, non-profit housing organizations, bankers, and other interested community members who have been willing to look at housing in alternative ways.

These efforts have been guided by the principles that housing must be stable, controlled by the individual, and integrated in the general community. One of the lessons learned from these efforts is the importance of separating housing and support services. When housing and support services are tied together, individuals are vulnerable to funding changes and other pressures effecting the agency providing support. Furthermore, people are less free to change agencies from which they receive support services.

There are now numerous alternatives to pursue in assisting a person with a disability to acquire a home including the use of trust funds, housing co-operatives, subsidies and other creative funding strategies. Opportunities exist and can be created to meet an individual's preferences and circumstances. Because the idea of home ownership is so new, it is helpful to learn from others' experiences. The last section of this packet contains several resources that should be helpful.

Support

Traditionally, people with developmental disabilities have received most of their assistance from formal service providers. In addition, this assistance has been heavily influenced by funding, existing service arrangements and practices, and the fact that many people lack relationships with people outside of the service system.

In creating the opportunity for individuals with developmental disabilities to live as integrated members of their community, the term "support" has come to mean a different way of developing assistance. The support a person receives might come from service organizations or from informal and personal relationships. In most cases, it is a combination.

For people whose assistance has come solely from the service system, a first step in arranging support is to create the opportunity for people to get involved in their communities and to develop personal relationships. It takes a great deal of time, attention, and flexibility to facilitate informal support. But, in many cases, individuals are getting assistance in more natural ways and are less reliant on the service system. Informal supports, however, should not be

used simply to avoid obstacles within the service system or to shift responsibility to people's families and friends. Many people will always need and choose to have formal services. Services that are based on a support approach are often described as "self-determined," "person centered," or "consumer controlled." This reflects the need to shift control so that the people receiving services are directing them.

Person Centered Planning

Person centered planning basically refers to a process of assisting people with developmental disabilities to identify and get the supports and services they need to live in their own homes, work, develop personal relationships, and get involved in their communities. It is distinguished from planning that is traditionally conducted and controlled by services organizations. Person centered planning is based on the assumption that what people want and need requires change within service organizations and communities and is designed as one tool to facilitate change.

An increasing number of service providers are attempting to implement this planning approach. Those that are successful take into consideration the great amount of resources, commitment, and change that it requires and are implementing it with small numbers of people at a time. Other agencies are adapting the approach for large numbers of people. In these cases, the process and outcomes are not significantly different from traditional planning. For an overview of the different types of person centered planning and a discussion of its benefits and limitations, see Finding a way toward everyday lives: The contribution of person centered planning (O'Brien & Lovett, 1992) that is listed in the annotated bibliography section.

Individualized Funding

In a few states (New Hampshire and Connecticut are examples), individualized, person-controlled funding is made available to at least some people. In contrast to the traditional rate-setting approaches used in most states, individualized approaches include developing a person-centered plan with people who care about the individual; based on that plan, developing a budget to cover the unique supports the individual needs; exercise of a variety of means by which the person or his/her representative can purchase the supports identified in the plan; and openness to flexibility and change so that as plans and needs change, supports can change as well.

This approach is so new that not much has been written about it as yet. States are discussing various means of implementing the approach, including direct cash payments and vouchers. The key is that the individual and/or his or her support network must control what supports are purchased and how they are organized. We believe that more states will experiment and move toward full implementation of an individualized funding approach.

Service Brokerage

While most systems utilize the traditional case manager or service coordinator to assist people in obtaining services, some are looking at the "service broker" or "resource consultant" as a person who could assist individuals and their networks to create a support package. This person could have a number of functions: teaching people and their networks about

the resources and choices they have; helping people and their networks to develop their individualized plan and budget; assisting people and their networks in negotiating contracts or in other ways spending the support dollars that have been committed to them; and monitoring to ensure that people's choices are being honored and to assist if changes must be made. The service brokerage concept was developed in Canada, has been tried in England, and is under intense discussion in this country.

WHERE TO GO FOR MORE INFORMATION

This section lists some of the many resources available about supported living and related issues. Included here are organizations that can provide further resources, annotations of written materials, and descriptions of several internet sites.

Organizations

Communitas, Inc.
730 Main Street
Manchester, CT 06040
(203) 645-6976

Communitas, Inc. is an organization that assists people to network, provides educational materials, conducts seminars and conferences, and stimulates creative projects concerning the full participation of children and adults with disabilities in community life. The organization offers several resource materials that may be helpful, including The Whole Community Catalogue.

National Home of Your Own Alliance
Institute on Disability
University of New Hampshire
7 Leavitt Lane, Suite 101
Durham, NH 03824-3512
1-800-220-8770

The National Home of Your Own Alliance is a technical assistance center funded by a cooperative agreement with the Administration on

Developmental Disabilities. The Alliance is currently working in eight states to develop local demonstrations of home ownership and control. The Alliance intends to negotiate in 23 states over the next five years, building coalitions of housing and disability organizations led by individuals with disabilities, their families, friends, and advocates.

In addition to technical assistance, the Alliance is developing a national information clearinghouse and conducting policy research and evaluation in collaboration with the Center for Accessible Housing in North Carolina, United Cerebral Palsy in Washington, D.C., Coop Initiatives in Connecticut, Institute on Disability at Temple University in Pennsylvania, and the Human Services Research Institute in Massachusetts. Its goal is to leave in place an infrastructure of exemplary practices and public and private partnerships, linking the home mortgage and social service industries to better serve people with disabilities.

National Resource Center
on Community Integration
Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280
1-800-894-0826
Contact: Steven J. Taylor, Director

The Center on Human Policy (CHP) is a national center which provides technical assistance, training, and information on supporting people with the most severe disabilities in the community. As part of its work concerning individualized services for adults, the CHP provides information and

assistance to promote a variety of service approaches, including home ownership by people with disabilities, the separation of housing and support components, individualized and flexible support for social integration, ties between individual assessment, planning, and funding, and control by people with disabilities of housing and services.

Research and Training Center on Community Living
University of Minnesota
University Affiliated Programs
212 Pattee Hall
150 Pillsbury Drive, S.E.
Minneapolis, MN 55455
(612) 624-9344
Contact: Charlie Lakin

This national center carries out research, training, and technical assistance activities related to integrated community living for people with developmental disabilities. Areas of concentration include: evaluation and technical assistance for deinstitutionalization and community services for individuals with severe disabilities living in the community, establishing and maintaining social relationships and networks, self-determination and self-advocacy, recreation and leisure activities, alternative communication methods, service financing and quality assurance, assistive devices, crisis intervention and behavioral support capacity building, personnel recruitment, and training and retention.

Community Living

TITLE: Community living for adults

AUTHOR: Center on Human Policy

PUBLICATION INFORMATION: 1989

Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-22280
1-800-894-0826

This newsbulletin presents and summarizes some concepts about supported living. It includes stories which describe the lives of a number of individuals who are living in their own homes and apartments and gives an overview of several agencies that have adopted an individualized approach to services. Though much has changed in the area of supported living since the development of this bulletin, its contents are still relevant.

TITLE: Living with the questions: Notes from a gathering of people concerned with supported living

AUTHOR: O'Brien, J., & Lyle O'Brien, C.

PUBLICATION INFORMATION: 1995

Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280
1-800-894-0826

This report was generated from a gathering of innovators in the supported living movement including: people with disabilities, family members, service providers, and system managers. Participants of the gathering drew upon their experiences to describe issues related to supporting people to live in their communities. Their experiences provide an in-depth understanding of this process. Topics include contradictions with system rules, how support makes a difference in people's lives, concerns in the day-to-day work of service providers, and strategies for growth of supported living. The report ends with reflections by several participants.

TITLE: Supported living: What's the difference?

AUTHOR: O'Brien, J.

PUBLICATION INFORMATION: 1993

Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280
1-800-894-0826

In this article O'Brien distinguishes between supported living and other service approaches. He argues that understanding supported living requires a reconsideration of assumptions and behavior toward people with

disabilities. The article begins with descriptions by service providers who have pioneered the approach of experiences which have enabled them to step outside the assumptions and practices that usually govern service providers. This is followed by the identification of issues that should govern supported living services and a concluding list of the obligations of service providers to individuals and their friends and families.

TITLE: The variety of community experience: Qualitative studies of family and community life

AUTHOR: Taylor, S. J., Bogdan, R., & Lutfiyya, Z. M. (Eds.)

PUBLICATION INFORMATION: 1995

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624
1-800-638-3775

This book looks at life in the community from a unique perspective. It contains studies which look at community participation from the vantage point of people with developmental disabilities, their families, and the community. This purpose of the book is not to describe or promote specific support strategies, practices, or other good ideas, but to explore how life in the community is experienced directly by those with developmental disabilities and their families, whether or not they are involved in the human services systems.

The studies reported in this book address one or more of three major themes including: family life, the nature of community (whether defined in

terms of associations and groups or geographically), and the nature of human services. This book contributes to general understandings but also provides useful insights and lessons to policymakers, people with developmental disabilities, family members, professionals, advocates, and others interested in life in the community.

TITLE: Cultivating thinking hearts: Letters from the Lifesharing Safeguards Project

AUTHOR: Zipperlen, H., & O'Brien, J.

PUBLICATION INFORMATION: 1994

Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280
1-800-894-0826

This paper is an exploration of the rich mix of concepts that arise from and apply to the creation of effective safeguards for lifesharing households (where people with and without disabilities choose life together). It includes essays and letters from the different perspectives of people involved in these situations.

TITLE: Innovation in the way people with disabilities can be supported to live and participate in community life

AUTHOR: Chernets, G.

PUBLICATION INFORMATION: 1995

In L. Nadel & D. Rosenthal (Eds.), Down syndrome: Living and learning in the community (pp. 256-262). New York: Wiley-Liss, Inc.

This chapter, written by a parent of three daughters, two of whom have disability labels, describes the development of two housing cooperatives and a support organization which works in conjunction with cooperatives to support members with disabilities. The coops--Courtyard and Chord--are committed to the creating of welcoming, inclusive, supportive communities representing people of various ages, income levels, abilities, and cultural origins. The support organization, NABORS, works in conjunction with the coop communities. In addition to describing the philosophy and organizational structure of the coops and NABORS, the author discusses some of the experiences of her daughter, Kerrie, within the coop.

TITLE: Exemplary practices in the quest towards homeownership

AUTHOR: Duncan, R.

PUBLICATION INFORMATION: 1996

The National Home of Your Own Alliance
c/o The Center for Universal Design
NC State University, School of Design
Box 8613
Raleigh, NC 27695-8613
1-800-220-8770

Many individuals, family members, and local or state agency staff who are interested in homeownership ask how to structure the process and how hurdles have been overcome by those who have been successful. There are many ways to balance and structure the frequently complex variables that need to be combined to achieve homeownership. This report is the compilation of collected data from twenty homeownership programs around the country that range from local programs run by non-profit service providers to state-wide projects based in state agencies. The report lists public financing sources, flexible under-writing guidelines from commercial banks, average household size, roommate characteristics, income averages, income sources, and more.

TITLE: Housing InfoPak

AUTHOR: Duncan, R.

PUBLICATION INFORMATION: 1995

The National Home of Your Own Alliance
c/o The Center for Universal Design
NC State University, School of Design
Box 8613
Raleigh, NC 27695-8613
1-800-220-8770

This InfoPak focuses on finding housing and obtaining financing as well as alternative ownership options for people with developmental and other disabilities. The resources listed in this InfoPak include financing sources, government agencies, private non-profit organizations, and other relevant groups and publications.

TITLE: Supports and Personal Planning InfoPak

AUTHOR: Duncan, R.

PUBLICATION INFORMATION: 1995

The National Home of Your Own Alliance
c/o The Center for Universal Design
NC State University, School of Design
Box 8613
Raleigh, NC 27695-8613
1-800-220-8770

This InfoPak focuses on obtaining and managing the support services and personal assistance that play a vital role in person-owned and controlled housing. Individuals and households who are in transition from agency controlled situations will need to arrange money management, medical services, transportation, access to employment, access to retail and public services, and access to recreational opportunities. The resources listed in this InfoPak include government agencies, private non-profit organizations, and other relevant groups and publications.

TITLE: Guidebook on consumer controlled housing

AUTHOR: Field, T., & Lakin, C.

PUBLICATION INFORMATION: 1995

Publications Office
Institute on Community Integration
University of Minnesota
109 Pattee Hall, 150 Pillsbury Drive, SE
Minneapolis, MN 55455
(612) 624-4512

This guidebook outlines basic principles, considerations, and service strategies in choosing and securing consumer controlled-housing for persons with developmental disabilities. It also includes assessing the need for and obtaining home modification planning for long-term supports and sources of assistance.

TITLE: New Hampshire's Home of Your Own Final Report

AUTHOR: Klein, J., & Black, M.

PUBLICATION INFORMATION: 1994

The National Home of Your Own Alliance
c/o The Center for Universal Design
NC State University, School of Design
Box 8613
Raleigh, NC 27695-8613
1-800-220-8770

The New Hampshire Home of Your Own demonstration project was designed to develop, implement, evaluate, and disseminate an approach to assist individuals with disabilities to secure their own homes and be fully included in their communities. The final report, submitted to the U.S. Administration on Developmental Disabilities, provides an overview and summary of the demonstration project conducted in New Hampshire from September 1, 1991 to August 31, 1994.

TITLE: 1995 Policy Retreat Proceedings

AUTHOR: Klein, J., & Black, M. (Eds.)

PUBLICATION INFORMATION: 1995

The National Home of Your Own Alliance
c/o The Center for Universal Design
NC State University, School of Design
Box 8613
Raleigh, NC 27695-8613
1-800-220-8770

The National Home of Your Own Alliance sponsored a two-day policy retreat in April 1995 in Portsmouth, New Hampshire, to bring together home owners, advocates, social service agencies, state and federal administrators, and representatives from other organizations with a shared interest in supporting individuals with disabilities to own and control their homes. The goal of the retreat was to identify barriers and opportunities encountered in this work, share information, collaborate effectively on

initiatives, and influence policy. These proceedings describe the barriers, identified needs, opportunities, suggestions and action plans discussed. The appendix includes a complete participant list.

TITLE: Toward a home of one's own: A workshop for families on the journey

AUTHOR: Ludlum, C. D.

PUBLICATION INFORMATION: 19950

The National Home of Your Own Alliance
c/o The Center for Universal Design
NC State University, School of Design
Box 8613
Raleigh, NC 27695-8613
1-800-220-8770

The training manual for this workshop was developed by people with disabilities, parents, and members of the National Home of Your Own Alliance. The manual is designed to assist parents, siblings, and individuals with disabilities in the process of allowing someone who has been viewed as vulnerable to move out into the world and to develop an interdependent support network consisting of family members, friends, neighbors, and personal assistants. Through story sharing, panels, and discussion groups, everyone comes to see the issues from a number of angles and different perspectives.

TITLE: A report on legal and financial planning issues in the Home of Your Own Project

AUTHOR: MacIntosh, J. D.

PUBLICATION INFORMATION: 1995

The National Home of Your Own Alliance
c/o The Center for Universal Design
NC State University, School of Design
Box 8613
Raleigh, NC 27695-8613
1-800-220-8770

As states move from a residential support model focused on a "provider" or "agency" to options where an individual leases or owns his own home, significant legal and financial planning issues emerge involving state and federal employment laws, IRS regulations, and Medicaid eligibility. This report addresses no only pitfalls that policy makers, provider of services, individuals with disabilities and their families may encounter, but also trust and guardianship issues. Other areas of discussion include preserving eligibility for and maximizing the use of Medicaid benefits and Department of Labor and IRS issues in supporting people with disabilities in their own homes.

TITLE: A survey of legal and financial planning issues in the Home of Your Own (HOYO) Project

AUTHOR: Macintosh, J. D.

PUBLICATION INFORMATION: 1994

University of New Hampshire
Institute on Disability
7 Leavitt Lane, Suite 101
Durham, NH 03824
1-800-220-8770

Based on the experience of supporting people in New Hampshire and other states to own homes, this article provides an overview of some of the "pitfalls and potential solutions" to legal and financial issues. It is divided into two major sections. The first section addresses how to preserve eligibility for and maximize the use of Medicaid benefits. The second section addresses Department of Labor and IRS issues such as how to arrange companion and roommate support.

TITLE: Letting go, moving on: A parent's thoughts

AUTHOR: Moore, C.

PUBLICATION INFORMATION: 1993

In J. A. Racino, P. Walker, S. O'Connor, & S. J. Taylor (Eds.), Housing, support, and community: Choices and strategies for adults with disabilities (pp. 189-204). Baltimore: Paul H. Brookes Publishing Co.

Cory Moore was a professional in the developmental disability service system as well as a parent of a child with a disability. She wrote this chapter from her parent perspective. It describes the experience of supporting her daughter to move away from home; first to live in a group home and eventually a home of her own. Many parents will find the chapter helpful as

she relates the feelings and dilemmas she experienced and shared with other parents in this process. She discusses the limitations of group home living and the advantages and risks of home ownership.

TITLE: National Home of Your Own Alliance Newsletter

AUTHOR: National Home of Your Own Alliance

PUBLICATION INFORMATION:

The National Home of Your Own Alliance
c/o The Center for Universal Design
NC State University, School of Design
Box 8613
Raleigh, NC 27695-8613
1-800-220-8770

Published 3 times a year, this newsletter highlights initiatives for home ownership and control in states receiving technical assistance from the Alliance. Also included are late breaking news items about housing issues and information on Alliance activities in the states and around the country.

TITLE: Extending the American dream: Home ownership through creative financing

AUTHOR: New Hampshire Home of Your Own Project

PUBLICATION INFORMATION: 1995

Institute on Disability
University of New Hampshire
7 Leavitt Lane, Suite 101
Durham, NH 03824
1-800-220-8770

The Home of Your Own Project in New Hampshire was designed to promote home ownership for people with disabilities. One of the activities of this project was to demonstrate that people with developmental disabilities have the financial capacity to sustain home ownership and how services can be designed to support people in these situations on an ongoing basis. This report provides a profile of 16 people who now own their own homes through working with this project.

TITLE: Down stairs that are never your own: Supporting people with developmental disabilities in their own homes

AUTHOR: O'Brien, J.

PUBLICATION INFORMATION: 1994

A reprint of this article from Mental Retardation, 32(1), 1-6 is available from:

Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280
1-800-894-0826

This article discusses the historical and current meanings and dimensions of "home" for people with developmental disabilities. O'Brien's

analysis of the meaning of home provides a framework for understanding the lack of opportunity that people with severe disabilities have experienced. He points out the obstacles to acquiring a home presented by the disability service system and discusses the need to create opportunities for home ownership along three dimensions: sense of place, control, and security. Lastly, O'Brien discusses the need for more supportive relationships between individuals with disabilities and the people in their lives if these efforts are to be successful.

TITLE: Housing for people with severe disabilities: A collection of resource materials

AUTHOR: Prepared by O'Connor, S., & Racino, J. Updated by Hulgin, K., Walker, P., Fisher, E., Handley, M., & Shoultz, B.

PUBLICATION INFORMATION: 1995

Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280
1-800-894-0826

This packet is an update of a 1990 information package and provides an introduction to housing strategies such as trusts, co-operatives, and subsidies. It offers information about organizations and other resources that should be helpful to individuals, their families, advocates, and service providers in the effort to develop home ownership opportunities.

TITLE: Housing policy and persons with mental retardation--A report of the working group on housing to the Presidential Forum: The President's reform agenda and people with mental retardation and the President's Committee on Mental Retardation

AUTHOR: President's Committee on Mental Retardation

PUBLICATION INFORMATION: 1995

President's Committee on Mental Retardation
Room 5325, 300 Independence Avenue, S.W.
Washington, DC 20201
Contact: Gary Blumenthal
(202) 619-0634

This report to the President's Committee on Mental Retardation lays out 10 broadly recommended goals in housing for persons with mental retardation, and then addresses 5 questions to policy and programmatic actions to contribute to the Committee's efforts to achieve the goals. These 5 questions include:

* What is currently known about housing for persons with mental retardation and what needs to be learned about it?
* What are the emerging successful and promising practices in policy and programs in providing normal housing for persons with mental retardation?
* What is the nature and organization of current federal, state and local housing and associated programs that affect housing for persons with mental retardation?

* What are the existing challenges and barriers in current policy and practices that impede access to the housing people want and need?
* What should the federal and state governments do and encourage others to do that will improve access to appropriate desirable housing for persons with mental retardation?

TITLE: Housing, support, and community: Choices and strategies for adults with disabilities

AUTHOR: Racino, J. A., Walker, P., O'Connor, S., & Taylor, S. (Eds.)

PUBLICATION INFORMATION: 1993

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624
1-800-638-3775

This book provides an in-depth look at and analysis of the issues related to supporting adults with disabilities to live in their own homes. It is divided into three parts. In Part I, several chapters address the complexities of a housing and support approach compared with traditional approaches. Issues discussed here include the importance of separating housing and support, choice and decision-making, support versus supervision, and changing roles of organizations.

Part II and III of this book provide personal and organizational perspectives related housing and support efforts. Part II consists of four essays, including one by a parent and three by individuals themselves, which

provide first hand accounts of the challenges and opportunities of getting their own homes. The last part of this book contains five case studies of organizations that have implemented the concepts and principles discussed in Part I.

TITLE: Housing is for everyone: Affordable homes for people with disabilities

AUTHOR: Raymond, B.

PUBLICATION INFORMATION: 1992

The New Hampshire Developmental Disabilities Council
Concord Center
10 Ferry Street, Box 315
Concord, NH 03301
(603) 271-3236

This booklet, though written to offer specific advice to New Hampshire residents, is a very good overview of housing options. It includes chapters that explain home ownership, public assistance programs, cooperatives, mortgage programs, and supports. The booklet is written clearly, simply, and includes concrete strategies.

TITLE: From a community residence to a home of their own

AUTHOR: Walker, P.

PUBLICATION INFORMATION: 1995

Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280
1-800-894-0826

This report describes how the Syracuse Developmental Services Office in Syracuse, New York facilitated the process of home ownership for two women previously living in a community residence.

TITLE: Not just a place to live: Building community in Toronto

AUTHOR: Walker, P., & O'Connor, S.

PUBLICATION INFORMATION: 1996

Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280
1-800-894-0826

This case study describes the formation of two housing cooperatives in Toronto. The coops were formed by a group of people with and without disabilities, who also formed another organization, Neighbours Allied for Better Opportunities in Residential Supports (NABORS), which serves as a vehicle to generate support for participation of members with disabilities. This report describes the background and organization of the coops and NABORS. In addition, it discusses strategies to create diversity, along many dimensions, within the coops as well as to create intentional community rather than just cooperative living.

TITLE: Creating individual supports for people with developmental disabilities: A mandate for change at many levels

AUTHOR: Bradley, V. J., Ashbaugh, J. W., & Blaney, B. C. (Eds.)

PUBLICATION INFORMATION: 1994

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624
1-800-638-3775

This book addresses the need for change at all levels of the service system in the effort to develop integrated services. The beginning chapters discuss the conceptual changes which are driving the shift to individualized services. Other sections of the book address change at the system and organizational levels. Several chapters describe mechanisms for change such as legislation, self-advocacy, and planning.

TITLE: Parent power: Change through grassroots networking

AUTHOR: Farber, A., & Marcel, K.

PUBLICATION INFORMATION: 1994

In V. J. Bradley, J. W. Ashbaugh, & B. C. Blaney (Eds.), Creating individual supports for people with developmental disabilities: A mandate for change at many levels (pp. 373-385). Baltimore: Paul H. Brookes Publishing Co.

This book chapter describes an effort driven by parents in Louisiana to change the state's service system. In the late 1980s, many parents in this state were frustrated with the lack of alternatives to institutionalization that existed for their children with severe disabilities. Beginning in 1988, parents joined other advocacy groups and policymakers to develop a vision of family support and supported living, design and push through supportive legislation, secure funding, and develop services. This chapter describes those efforts as well as the lessons learned from parent involvement in changing the service system.

TITLE: Creating support based on the person versus the system: The story of an organizational change

AUTHOR: Fratangelo, P., with an Introduction by Taylor, S., & Hulgin, K.

PUBLICATION INFORMATION: 1994

TASH Newsletter, 20(3), 16-21.

This article is written by the Director of Onondaga Community Living (OCL), a small agency in Syracuse, New York. She describes the beginning stages of this agency's effort to implement person-centered services. The article includes OCL's mission statement and a discussion of the process of creating a common vision and the challenges of implementing it.

A separate introduction to this article describes the important role OCL plays in promoting the development of individualized services within the

service system. It identifies the characteristics of the agency that contribute to its capacity to develop this approach and therefore create change from the bottom up.

TITLE: Jay Nolan Community Services: The challenges and dilemmas of quick conversion from group homes to supported living services

AUTHOR: Hulgin, K.

PUBLICATION INFORMATION: 1996

Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280
1-800-894-0826

This report is based on a visit to Jay Nolan Community Services, located in Los Angeles, in November, 1995. The agency supports about 60 people, many of whom have autism and a history of challenging behavior. Approximately three years prior to this visit, the agency began a process of converting from group home services to supported living services. The report describes the circumstances that led to movement in this direction and the considerations and characteristics of the agency that influenced the decision to make this change quickly. It also includes examples of how the agency developed supported living services for two specific individuals with complicated needs.

TITLE: Job Path: Shifting the focus beyond work

AUTHOR: Hulgin, K., & Searl, J.

PUBLICATION INFORMATION: 1995

Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280
1-800-894-0826

This report is based on a visit to Job Path, an agency located in New York City, in February, 1995. Though the agency has primarily provided employment services, it recently expanded its efforts to supports a small number of people with severe disabilities in their social and living situations.

The report describes the process the agency has gone through in developing these services. It also includes examples of how services have been provided to two specific individuals.

TITLE: IMPACT: Feature issue on supported living, Volume 8(4), Autumn 1995

AUTHOR: Institute on Community Integration (Ed.)

PUBLICATION INFORMATION: 1995

Institute on Community Integration
109 Pattee Hall, 150 Pillsbury Drive, SE
University of Minnesota
Minneapolis, MN 55455
(612) 624-4512

In this issue of IMPACT, leaders in the development of supported living describe the challenges, issues, and accomplishments of this movement. Articles describe projects and efforts at the national, state, agency, and individual level. Also included are resources related to these efforts.

TITLE: The journey to inclusion: A resource guide for state policymakers

AUTHOR: Jaskulski, T., Lakin, C., & Zierman, S.

PUBLICATION INFORMATION: 1995

President's Committee on Mental Retardation
Room 5325, Cohen Building
330 Independence Avenue, S.E.
Washington, DC 20201
(202) 619-3636

This guidebook was developed as a resource for the National Collaborative Academy sponsored by the President's Committee on Mental Retardation. It describes the enormous changes taking place in the lives of people with mental retardation in all aspects of community living. It relies heavily on descriptions of state initiatives and exemplary programs, along with stories about and by people with mental retardation.

TITLE: Direct dollars: A study of individualized funding in Canada

AUTHOR: L'Institut Roeher Institute

PUBLICATION INFORMATION: 1993

The G. Allan Roeher Institute
Kinsmen Building, York University
4700 Keele Street
North York, ON M3J 1P3
CANADA
(416) 661-9611

This book describes research that was part of a series of studies conducted by the Roeher Institute on the creation of a service system in Canada that is directed by the people receiving services as well as more equitable and cost-effective. This study focuses on individualized funding, or the practice of giving money directly to people with disabilities and their families. It describes the general concept of individualized funding and examines current funding arrangements and their relation to individualized funding. It explores specific models of individualized funding and analyzes the implications of individualized funding from the perspectives of consumers, service providers, social service agencies, and the social welfare field. This study also briefly explores the applicability of individualized funding to other types of services such as vocational services, housing, child care, transportation, and education.

TITLE: Supported living monograph, Volume II

AUTHOR: National Association of Private Residential Resources

PUBLICATION INFORMATION: 1992

NAPRR
4200 Evergreen Lane, Suite 315
Annandale, VA 22003
(703) 642-6614

This monograph was prepared for a conference on Supported Living sponsored by NAPRR in February, 1992. It includes a book chapter by Jay Klein on home ownership, an article by John O'Brien and Connie Lyle O'Brien about organizational issues related to supported living, and several other articles. The appendix includes lists of other resource materials. This monograph is priced as follows: Prepaid: $25; Billed orders: $30.

TITLE: Community Services Reporter

AUTHOR: National Association of State Directors of Developmental Disability Services, Inc.

PUBLICATION INFORMATION: Monthly

NASDDDS
113 Oronoco Street
Alexandria, VA 22314
(703) 683-4202

This monthly publication includes articles about general issues in developing community services and innovative practices around the country. Each issues also contains resources such as publications, videos, and conferences.

TITLE: An affirmation of community: A revolution of vision and goals

AUTHOR: Nerney, T., & Crowley, R. F.

PUBLICATION INFORMATION:

Monadnock Developmental Services
Region V Area Agency
Keene, NH

In 1993, Monadnock Developmental Services, a non profit regional agency in New Hampshire, was awarded a grant from the Robert Wood Johnson Foundation for the purpose of creating a local system of services that supports self-determination. This manuscript was developed as a plan or guide in that process. It provides an overview of the values and vision of the agency and six specific goals including: self-determined personal supports, integrated housing, elimination of the congregate model, inclusive education, equal access to employment, and universal physical accessibility. The second part of the manuscript describes how the system and funding mechanisms would have change to support a service plan that is developed by individuals and the people closest to them. The concepts of circles of support, service brokerage and individualized funding are emphasized.

TITLE: Deliberate-fire: An account of organizational transformation in Onondaga Community Living

AUTHOR: O'Brien, J.

PUBLICATION INFORMATION: 1996

TASH Newsletter, 22(1), 27-29.

This article was generated from an external evaluation of Onondaga Community Living (OCL), a small agency in Syracuse, New York. The evaluation report, presented here in abbreviated form, explains the accomplishments and challenges of this agency's effort to develop individualized services. The effort began by developing individualized services for new people as they came into the agency and providing opportunities for members to learn about the approach. This article identifies the specific capacities that members developed in this process.

The greatest challenge OCL faced was the fact that the commitment to individualized services grew among members of the agency faster than it was able to provide them. This article describes the dilemmas related to the growing demands for individualized services from people living in the agency's group homes and ideas for developing new resources to address them.

TITLE: Remembering the soul of our work: Stories by the staff of Options in Community Living, Madison, Wisconsin

AUTHOR: O'Brien, J., & Lyle O'Brien, C. (Eds.)

PUBLICATION INFORMATION: 1992

Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280
1-800-894-0826

This is a collection of 150 stories written between 1987 and 1991 by staff from Options in Community Living of Madison, Wisconsin, an agency that pioneered the supported living movement. Their stories effectively communicate some of the qualities that make their work meaningful.

TITLE: More than just a new address: Images of organization for supported living agencies

AUTHOR: O'Brien, J., & Lyle O'Brien, C.

PUBLICATION INFORMATION: 1991

Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280
800-894-0826

In this paper, O'Brien explains the need for new ways of thinking about organizations and of organizing to implement a supported living approach. He explains that supported living involves a new mindset in working with people, one which is not compatible with many existing service organizations. More responsive organizations will facilitate positive relationships with people receiving services and the opportunity for continuous learning from the effort to support them. The paper includes ideas for building new structures and uses of power within agencies. For example, it describes a new way of building effective teams and responsibilities of directors. The

paper concludes with a discussion of the need to view organizations as social units rather than the traditional machine image if these changes are to be implemented successfully.

TITLE: Framework for accomplishment

AUTHOR: O'Brien, J., & Lyle O'Brien, C.

PUBLICATION INFORMATION: 1990

Responsive Systems Associates
58 Willowick Drive
Lithonia, GA 30038
(770) 987-9785

Framework for accomplishment is a manual for a workshop on organizational change. It is an agency-change model based on three premises about human service agencies providing long-term support to people with disabilities: 1) service providers should assist people to discover and move toward a more desirable future; 2) service providers should offer assistance in ways that protect and promote valued experiences now; and 3) service providers should offer assistance in ways that support and strengthen communities. This manual outlines a five-day workshop to assess and develop the capacity of agencies to implement person-centered services.

TITLE: Service brokerage: Individual empowerment and social service accountability

AUTHOR: Salisbury, B., Dickey, J., & Cameron, C.

PUBLICATION INFORMATION: 1987

The G. Allan Roeher Institute
4700 Keele Street, Kinsmen Building
Downsview, ON M3J 1P3
CANADA
(416) 661-9611

Service brokerage, a concept that has been discussed for years, has been operationalized in British Columbia and is described in this small manual. In British Columbia, the concept was developed by parents of people with disabilities and is based on the belief that the standard ways of providing and funding services are inadequate. Service brokerage attempts to make systems more accountable to the people served by them and to put decision-making control in the hands of these people and their support networks.

This monograph provides an overview of the concept of service brokerage and clarifies some of the important aspects of implementing the approach. The concept of service brokerage is described here as one part of a three component system or "support nucleus" for individuals with disabilities and their families. The idea is that effective service brokerage must be complemented by individualized funding and a personal network which provides support to the individual in decision-making and enables monitoring of the services and supports that brokers being into place.

TITLE: Regenerating a community: The story of Residential, Inc.

AUTHOR: Shoultz, B.

PUBLICATION INFORMATION: 1993

In J. A. Racino, P. Walker, S. O'Connor, & S. J. Taylor (Eds.), Housing, support, and community: Choices and strategies for adults with disabilities (pp. 281-298). Baltimore: Paul H. Brookes Publishing Co.

This chapter is a case study of Residential, Inc., a small agency in rural Ohio that has reorganized its services from operating group homes to assisting people to live in homes of their own. The study describes some of the dilemmas they faced and strategies they developed in creating housing opportunities, including changing staff roles and developing better problem solving strategies. Their work eventually evolved into the effort to build a strong community and led them to develop the Perry County Housing Association which is also described in the chapter.

TITLE: Supported living: New directions in services to people with developmental disabilities

AUTHOR: Smith, G.

PUBLICATION INFORMATION: 1991

National Association of State Directors
of Developmental Disabilities Services (NASDDDS)
113 Oronoco Street
Alexandria, VA 22314
(703) 683-4202

This volume provides a comprehensive summary of supported living nationwide. It includes an overview of supported living and chapters on various state supported living programs, approaches to financing supported living, and the lessons being learned as states implement supported living programs.

TITLE: Life in the community: Case studies of organizations supporting people with disabilities

AUTHOR: Taylor, S. J., Bogdan, R., & Racino, J. A. (Eds.).

PUBLICATION INFORMATION: 1991

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624
1-800-638-3775

Based on a 21-state, 5-year study, this book reports on organizations around the country that have been the most successful in supporting individuals with disabilities to live in the community. Comprehensive case studies are organized around three themes--families and their children; housing, homes, and support for adults with disabilities; and the role of community and society in integration.

This in-depth look at agencies shows the variety of ways in which organizations are working to develop integrated services. Though they are

each unique, the last chapter of the book provides a summary of the characteristics that the most responsive agencies share such as: a guiding philosophy, openness to change, and committed and caring leadership.

TITLE: Coming home: From deinstitutionalization to supporting people in their own homes in Region VI, New Hampshire

AUTHOR: Walker, P.

PUBLICATION INFORMATION: 1993

Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280
1-800-894-0826

This report describes the efforts of the Area Agency for Developmental Services in Region VI, New Hampshire to shift from supporting people in group homes to supporting them in their own homes. It offers important lessons for agencies/regions facing the dual challenge of institutional closure and promoting quality of life in the community.

TITLE: Listen lady, this is my life

AUTHOR: Amado, A., & Lyon, P.

PUBLICATION INFORMATION: 1990

Human Services Research and Development Center
1195 Juno
St. Paul, MN 55116
(612) 696-0012

This is a booklet of stories about personal futures planning as it was implemented with agencies in Minnesota with strategies for systems change.

TITLE: Choice through knowledge, Knowledge = power

AUTHOR: Cotton, P., & Sowers, J.

PUBLICATION INFORMATION: 1995

Patty Cotton
Jo-Ann Sowers
(603) 228-2084

This manual was developed to provide an overview of services provided through an organization called Opus, Inc. in New Hampshire. The organization was formed in 1995 to assist individuals with disabilities and their families to determine the types of support they need and to get them either through formal or informal resources.

The emphasis of their efforts is on assisting people to understand and create alternative means of getting the supports they need such as hiring a service broker to find services through natural networks, professional business arenas, community services, and human service systems. Prior to choosing service providers, the agency assists individuals to define what they consider quality services and to conduct interviews with service providers. Once the providers are chosen, Opus, Inc. assists individuals and their families to secure the necessary funding which sometimes involves negotiating with the state. Finally, the agency assists people to evaluate the effectiveness of their supports over time.

Services through Opus, Inc. are paid for by the individual. Typically, funding agencies in New Hampshire allocate a sum of money to the individual to purchase facilitation and support for service planning.

TITLE: Building community one person at a time: One candle power

AUTHOR: Ducharme, G., Beeman, P., DeMarasse, R., & Ludlum, C.

PUBLICATION INFORMATION: 1994

In V. J. Bradley, J. W. Ashbaugh, & B. C. Blaney (Eds.), Creating individual supports for people with developmental disabilities: A mandate for change at many levels (pp. 347-360). Baltimore: Paul H. Brookes Publishing Co.

This chapter describes a project funded by the Connecticut Developmental Disability Council to implement the concept of circles of support with five individuals. Circles of support, as described, here consist of a six-part process designed to improve the lives of individuals with

disabilities. The process includes: 1) building on capacities of people and communities; 2) clarifying the vision and goals of the person with the disability; 3) building circles of support; 4) building bridges to community life; 5) starting small; and 6) changing systems. In this chapter, DeMarasse (who lived in an institution) and Ludlum (who lived with her family) tell how this process has helped them to move to homes of their own and gain membership in their communities.

TITLE: Personal relationships and social networks: Facilitating the participation of individuals with disabilities

AUTHOR: Lutfiyya, Z. M.

PUBLICATION INFORMATION: 1991

Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280
1-800-894-0826

This information packet includes an overview article, three articles which describe the experiences of people with disabilities who have nondisabled friends and are part of a network of people, and an annotated bibliography.

TITLE: Person-centered planning: Finding directions for change using personal futures planning

AUTHOR: Mount, B.

PUBLICATION INFORMATION: 1992

Graphic Futures, Inc.
25 West 81st Street, 16-B
New York, NY 10024
(212) 362-9492

This booklet presents the values and philosophy of person-centered planning in comparison with traditional practices. It includes a description of the planning process and the implications for long-term change for individuals and organizations.

TITLE: It's never too early, it's never too late: A booklet about personal futures planning

AUTHOR: Mount, B., & Zwernick, K.

PUBLICATION INFORMATION: 1988

Metropolitan Council
Mears Park Centre
230 East Fifth Street
St. Paul, MN 55101

This booklet provides a good overview of personal futures planning. It begins with a comparison of this approach with traditional planning methods. Then, through personal examples, the booklet describes the

components of the actual planning process. The last section discusses the role of personal futures planning in relation to Individual Habilitation Plans and in promoting systems change.

TITLE: A guide to life-style planning: Using *The Activities Catalog* to integrate services and natural supports

AUTHOR: O'Brien, J.

PUBLICATION INFORMATION: 1987

In B. Wilcox & G. T. Bellamy, A comprehensive guide to *The activities catalog: An alternative curriculum for youth and adults with severe disabilities*. Baltimore: Paul H. Brookes Publishing Co.

O'Brien presents life-style planning as a process that guides family members, friends, and service providers through three essential planning activities: 1) describing a desirable future with the person with a disability; 2) developing a schedule of activities and supports that will organize available resources to move toward that future; and 3) accepting responsibility for using available opportunities and dealing with the lack of needed activities and supports. This approach is based in the understanding that there are five basic accomplishments that should guide services for people with severe disabilities: community presence, community participation, choice, respect, and competence.

TITLE: Finding a way toward everyday lives: The contribution of person centered planning

AUTHOR: O'Brien, J., & Lovett, H.

PUBLICATION INFORMATION: 1992

Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280
1-800-894-0826

This monograph describes the foundation of person-centered planning, its limitations, the controversies among practitioners, and fears about its debasement. It also includes a brief description of different approaches including: Individual Service Design, Personal Futures Planning, MAPS, and Essential Lifestyle Planning.

TITLE: Telling new stories: The search for capacity among people with severe handicaps

AUTHOR: O'Brien, J., & Mount, B.

PUBLICATION INFORMATION: 1989

Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280
1-800-894-0826

This article tells the story of a man from two perspectives. It contrasts the story toll by traditional service plans with the effort to understand his life from a personal and capacity based perspective. The two stories differ in the way theywere constructed, in their purpose, in their consequence, and in the assumption they shape about human development and human service organization

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TITLE: Multiculturalism and disability: A collection of resources

AUTHOR: O'Connor, S.

PUBLICATION INFORMATION: 1993

Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280
1-800-894-0826

This information packet includes an overview article which offers a discussion on how disability should be included in the multicultural dialogue and an annotated bibliography of readings, organizations and other resources related to multiculturalism and disability. Topics include: attitudes, education, and system issues.

TITLE: Supporting people with severe reputations in the community

AUTHOR: Smull, M., & Harrison, S.

PUBLICATION INFORMATION: 1992

National Association of State Directors of
Developmental Disabilities Services (NADDDS)
113 Oronoco Street
Alexandria, VA 22314
(703) 683-4202

This handbook describes, using many practical examples, how people receive "severe reputations," how planning can be implemented with an individual for community living, how supports to implement the plan can be recruited, and how the frequent perversions of supported living for people with more severe disabilities can be avoided.

TITLE: Supports for community living: A case study

AUTHOR: Traustadottir, R.

PUBLICATION INFORMATION: 1991

Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280
1-800-894-0826

This report is based on a qualitative study which examines in detail the supports provided to one individual with severe disabilities and the role of this support in enabling him to become part of community life

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World Wide Web Sites on the Internet

Allen, Shea & Associates
URL: http://www.napanet.net/business/personal/ASA/ASA.html
1040 Main Street, Suite 200B
Napa, CA 94559
(707) 258-1326
FAX: (707) 258-8354
e-mail: ASA@NAPANET.NET

This group provides technical assistance and on this site they maintain articles on supported living, managed care, and person-centered planning, and other related information.

The Arc
URL: http://TheArc.org/welcome.html
500 East Border Street, Suite 300
Arlington, Texas 76010
Voice: (817) 261-6003
FAX: (817) 277-3491
TDD: (817) 277-0553
e-mail: thearc@metronet.com

The Arc web site offers information about their research, advocacy, and service efforts. It provides links to its local chapters, reprints of articles, and information about how to access other disability related information on the internet.

Center on Human Policy
URL: http://web.syr.edu/~thechp
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280
Voice: 1-800-894-0826
(315) 443-3851
TTY (315) 443-4355
FAX (315) 443-4338
email: thechp@sued.syr.edu

This site offers abstracts, articles, and other material related to the rights and community inclusion of people with disabilities.

Inclusion Press International
URL: http://inclusion.com/
24 Thome Crescent
Toronto, ON M6H 2S5
CANADA
(416) 658-5363 FAX: (416) 658-5067
e-mail: includer@idirect.com
Publishers: Jack Pearpoint and Marsha Forest

Inclusion Press is a small independent press striving to produce readable, accessible, user-friendly books and resources about full inclusion in school, work, and community. This site offers information about strategies for inclusion, books, videos, links to others sites, a recommended reading list, and information about workshops and conferences.

National Home of Your Own Alliance
URL: http://alliance.unh.edu/
Institute on Disability
University of New Hampshire
7 Leavitt Lane, Suite 101
Durham, NH 03824-0555
1-800-220-8770
VOICE/TDD: 603-862-4320
FAX: 603-862-0034
Email: IOD@unh.edu

This site provides information about technical assistance and resources to promote home ownership for people with disabilities.